

# Ethics briefings

## Altruism versus commercialism

Two recent announcements have again triggered the perennial debate about altruism versus commercialism. In Israel, the health minister has reversed a ban on the import of ova, which will allow people to pay for human eggs, imported primarily from Romania. This is the first time the Israeli government has allowed the purchase of body tissue or parts for medical use. The decision was taken in response to a High Court challenge to the 6 month old prohibition, by women who were unable to receive fertility treatment because of the shortage of donated eggs.<sup>1</sup> In the United States, where payment for donated eggs is now fairly routine, attention has shifted to the possibility of paying for human organs for transplantation. The ethics committee of the American Society of Transplant Surgeons is reported to have recommended a pilot programme to pay the funeral expenses incurred by donating families.<sup>2</sup> At the same time, a committee of the American Medical Association (AMA) had recommended that pilot studies be conducted to determine the effect of financial incentives for cadaveric organ donation on donation rate and on the values thought to be central to donation.<sup>3</sup> It is expected that this issue will be revisited at the AMA's annual meeting in Chicago in June when the AMA's House of Delegates will vote on a revised Report to decide whether the proposal should become AMA policy. Those promoting this type of commercialism often acknowledge that principles are giving way to pragmatism, and that the weight of moral argument lies on the side of altruism. Interestingly, however, the AMA Report would have proposed a slightly different approach arguing that: "If policymakers, ethicists, or legislators prohibit the implementation of programs that could be shown to increase the number of available organs and reduce the number of deaths, then they must bear some moral responsibility for the patients who die from lack of an organ transplant".<sup>3</sup>

All articles written by Veronica English, Gillian Romano-Critchley, Julian Sheather, and Ann Sommerville, BMA Ethics Department.

## Gamete donor anonymity

The UK government is seeking views about what information concerning donors should be available to children born as a result of egg, sperm, or embryo donation.<sup>4</sup> For those born or conceived before the proposals are adopted, this will be restricted to non-identifying information (because the Human Fertilisation and Embryology Act gives assurances that any shift to the release of identifying information about donors would not be applied retrospectively). But the more controversial question considered is whether future donors should be identifiable.

One of the major arguments of those who oppose such a change is that it will inevitably lead to a dramatic reduction in the number of donors available and, as a result, some people will be unable to obtain treatment. There is also a fear that those who want to use an anonymous donor, or who because of the expected drop in the number of donors are unable to receive treatment at a licensed clinic, will make private arrangements. This would not only evade the regulatory mechanism but could potentially put women at risk because of the absence of screening procedures. Those who argue for identifying information to be available focus almost exclusively on the rights of the children born following donor insemination to know their genetic origins.

It is assumed, in most of the debate on this subject, that providing identifiable information about donors will inevitably lead to more openness, but this assumption needs to be questioned. In Sweden, where children have had the right, since 1985, to request identifiable information about the donor, the vast majority of parents (89%) have not told their children that they were born following donor insemination and only 41% of these have said they plan to do so when the child is older.<sup>5</sup> If parents do not tell their children they were born following donor insemination, the fact that the donor's identity is accessible is irrelevant, because the children will not have the information available to enable them to make the decision to access it.

There is no definitive research showing the impact of the availability of

identifiable information on parents' decisions about whether to tell their children about their origins. It could make it easier for parents because they would have more information available to give to the child or, it could make it more difficult because the fact the child may want to trace the donor could be perceived as threatening. If the latter is the case and more families opt not to tell their children they were born following donor insemination, the search for more openness could in fact lead to more secrecy.

The deadline for receipt of comments to reach the government is 1 July 2002.

## Developments in public health ethics

Ethical problems confronting public health practitioners have, relatively speaking, received scant attention. No doubt this is in part due to the traditional emphasis in medical ethics on the dynamics of the doctor-patient relationship. In this model, the doctor is in a one-to-one relationship with a patient who has usually requested some form of treatment. Doctors in public health practice, by contrast, are concerned with the health interests of large groups, communities, or whole populations. They do not have individual patients, nor can the ethics of their practice be easily understood in terms of issues such as consent or duty of care, issues which are active in the traditional clinical model.

This relative lack of interest may be due to the inextricably political nature of decision making in this area. Concerned as it is with institutions, with macro projects and with population aggregates, public health is always going to be a tool of public policy.<sup>6</sup> This can affect ethical reflection on public health practices in several ways. Firstly, it can lead to ethical quietism. Doctors may feel it is for politicians to debate the merits and drawbacks of policy initiatives—that the moral arguments are for parliament—while they themselves are employed to implement them. In a similar vein, doctors may see their role as scientists—as information gatherers—and therefore as morally neutral: they gather the facts, others decide the policy initiatives that follow from them. Secondly, in comparison to the

provision of conventional health services, public health receives very little media or political attention. It generates far fewer press stories (although the interest generated by the recent discussion of the risks and benefits of the mumps, measles, and rubella (MMR) vaccination is an obvious exception), is the subject of far less litigation, and is therefore under less external pressure to scrutinise its codes of practice.

Nevertheless, there are signs of a fresh interest in the ethics of public health. The conflict between individual autonomy and the benefits of protecting the immunity of the group with widespread use of the MMR vaccination has been widely discussed. During its current revision of its book *Medical Ethics Today*,<sup>7</sup> the BMA has been asked to consider devoting a chapter to public health ethics. Reasons for this are various, but one can be clearly located in the development of the ethical debate over the “human right” to health, a debate that has intensified in the UK since the Human Rights Act came into force in 2000. Another, allied source might be found in the World Health Organisation’s (WHO) famous definition of health in the 1978 Declaration of Alma Ata as “a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity”. This definition is central to the WHO’s plan for the 21st century.<sup>8</sup> Not only is it as unashamedly normative as it is elusive of meaning—after all, what constitutes complete social wellbeing?—it also marks a shift from negative to positive conceptions of health. Just as health ceases to be a mere absence of disease, so public health shifts its focus from combating the causative factors of ill health, such as bacteria or chemicals, to the active development of a science of health improvement. Traditionally, public health has focused on goals that did not generate significant ethical controversy, such as cleaning up water supplies and providing good sanitation. The “new public health”, however, has expanded its remit to include

controlling, or attempting to control, the choices, or even the desires, of human beings. This is particularly true of some of the more obvious threats to health such as smoking and overeating.<sup>9</sup> It is this move from health protection to health promotion, this move from negative to positive definitions of health, that has given birth to a new set of ethical questions. These include a radical questioning of the appropriateness of applying analytical models developed in the study of non-human health threats to human volitions. Are randomised control trials, for example, the best method for analysing the complex and often mysterious motives behind drug-taking? It has also thrown into sharp relief the central importance of socioeconomic status in determining public health. The recognition that certain social conditions are a prerequisite for individuals to flourish has led to controversial calls for political change based on theories of distributive justice. The development of the “new public health” has also considerably intensified the traditional problem of paternalism in this field. Arguably, in trying to influence the pattern of human choice and motivation, public health practitioners are utilising scientific techniques in order to develop the power to alter people’s behaviour. Ethically it is not easy to reconcile this with values such as autonomy, integrity, responsibility or a respect for justice.

It is from areas such as these that fresh thinking on the ethics of public health is emerging, a development that may indeed, to echo the words of the minister for health, finally “take public health out of the ghetto”.<sup>10</sup>

## Assisted suicide

Dianne Pretty, who tried to use new human rights legislation to challenge the UK’s prohibition on assisted suicide, lost her case in the House of Lords at the end of 2001.<sup>11</sup> The Lords upheld the court of first instance’s view (discussed in detail in the last Ethics briefings<sup>12</sup>) that although permitting

assisted suicide would not be incompatible with the Human Rights Act (HRA), the state was not required to permit it. Research has shown that HRA points have only been upheld in one fifth of cases where they have been raised.<sup>13</sup> Mrs Pretty and her legal team plan to appeal to the European Court of Human Rights.

## References

- 1 Siegal-Itzkovich J. Israeli women can buy ova from abroad. *British Medical Journal*, 2002;**324**:69.
- 2 Ritter J. Is it time to pay for organs? *Chicago Sun-Times* 2002 Jan 6. [www.suntimes.com/output/health/cst-nws-organ06.html](http://www.suntimes.com/output/health/cst-nws-organ06.html) [accessed 18 January 2002].
- 3 Council on Ethical and Judicial Affairs. Encouraging pilot studies of financial incentives for organ donation. In: *American Medical Association—Proceedings of the House of Delegates 55th interim meeting, December 2001* [report not adopted]. USA: American Medical Association, 2001.
- 4 Department of Health. Donor information consultation. Providing information about sperm, egg and embryo donors. London: Department of Health, 2001. [www.doh.gov.uk/gametedonors](http://www.doh.gov.uk/gametedonors) [accessed 18 January 2002].
- 5 Gottlieb C, Lalos O, Lindblad F. Disclosure of donor insemination to the child: the impact of Swedish legislation on couples’ attitudes. *Human Reproduction* 2000;**15**:2052–6.
- 6 Beauchamp D E, Steinbock B. *A new ethics for the public’s health*. Oxford: Oxford University Press, 1999: 7–8.
- 7 British Medical Association. *Medical ethics today: its practice and philosophy*. London: BMA, 1993.
- 8 World Health Organization. *The medical profession and human rights: handbook for a changing agenda*. London: Zed Books, 2001:317.
- 9 Buchanan D R. *An ethic for health promotion: rethinking the sources of human well-being*. Oxford: Oxford University Press, 2000:4.
- 10 Quoted in: *The second report of the Health Committee of Session 2000–2001*, public health. London: The Stationery Office, 2001:xiv.
- 11 R v Director of Public Prosecutions (respondent), Ex Parte Dianne Pretty (Appellant) & Secretary of State for the Home Department (Interested Party) [2002] 1 All ER 1.
- 12 English V, Romano-Critchley G, Sheather J, et al. Ethics briefings: Human rights and assisted suicide. *Journal of Medical Ethics* 2002;**28**:53–4.
- 13 MacCallum V. Report shows that only one in five HRA points are upheld. *Law Society Gazette* 2002;**99**:5.